

Hearing the Voice of the PERSON with dementia

Sonya Barsness and Karen Stobbe

First four pages of slides used
with the Hand in Hand workbook

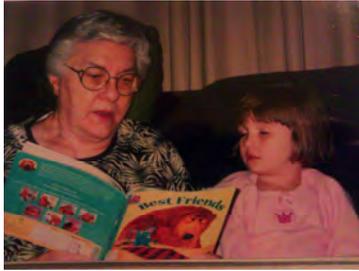














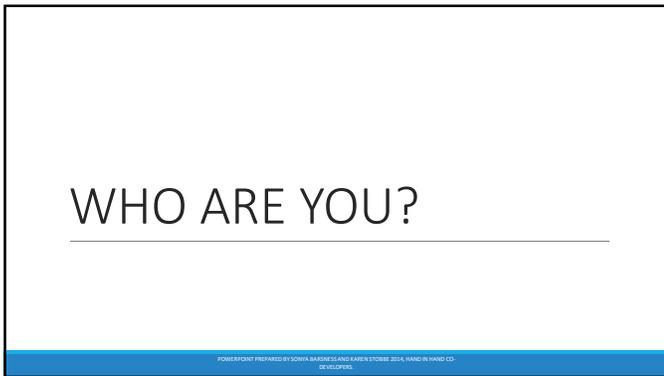






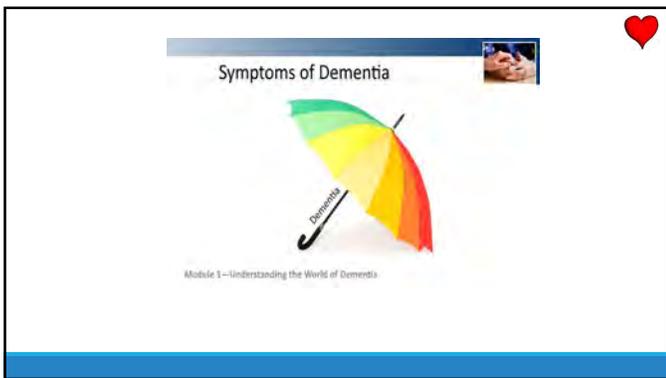


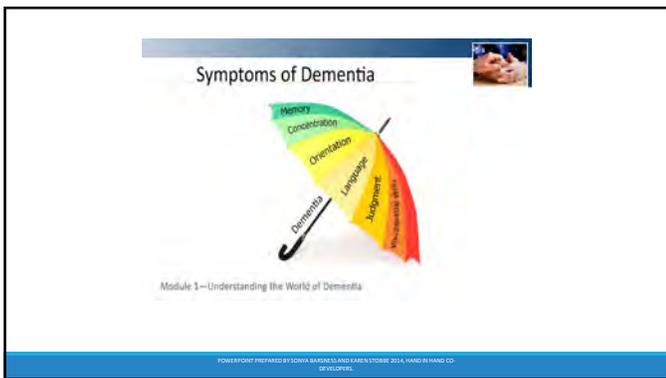












Every person is an individual.



ILLUSTRATION: GETTY IMAGES/ILLUSTRATION WORKS

Our Guiding Values

CAN'T → **HOW**

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Every person
has a right to
their best life.



KNOW EACH
PERSON



We
MUST
Change





Person-Centered Care

values choice,
dignity, respect,
self-determination
and purposeful living.



Person-Centered Care

honors an individual's goals
and preferences. Specifically
with dementia, this approach
looks past the diagnosis to the
person, emphasizing
communication and relationships
between caregivers and residents.



**Break down
Barriers**



Us Them
They We



Every person has a voice.



 *Being with Persons with Dementia Means...*

- Understanding things from their perspective.
- Being with persons with dementia “where they are”.
- Recognizing persons with dementia as whole individuals.

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 *Being with Persons with Dementia Means...*

- Building on strengths.
- Connecting with persons with dementia and validating them as human beings and as equals.
- Recognizing that sometimes the best way we can support persons with dementia is to just be with them, to sit with them, and to listen to them.

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How do we hear
the person?



Asking
Listening
Hearing
Watching
Knowing
Being

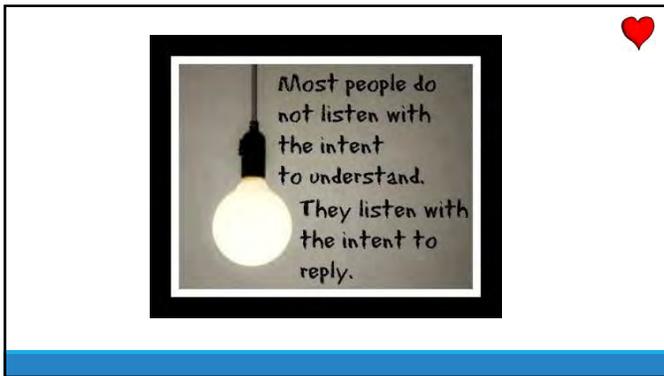
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to listen



EAR 聽 YOU
EYES
UNDIVIDED ATTENTION
HEART









What can you "hear"
with your eyes?

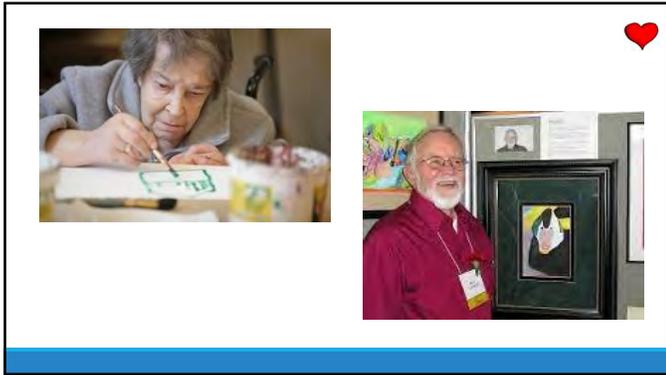
video

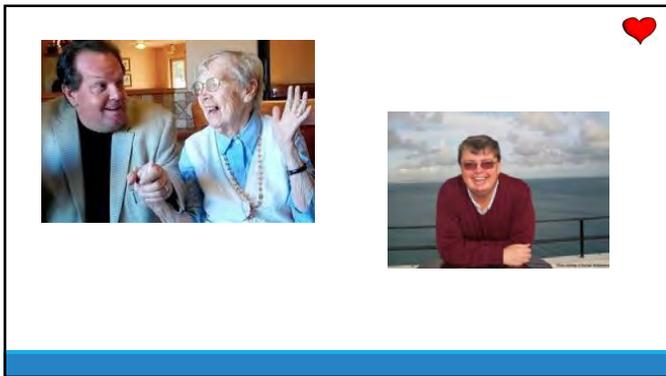
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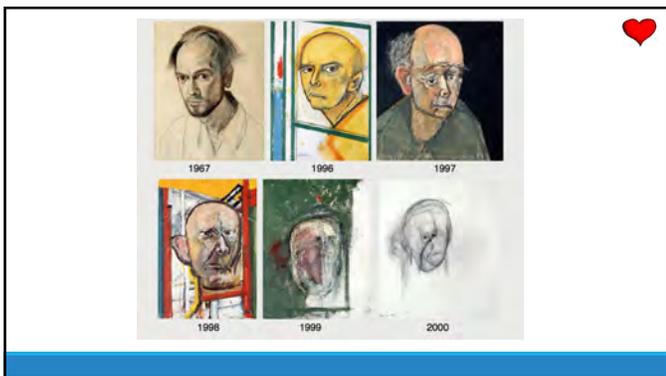


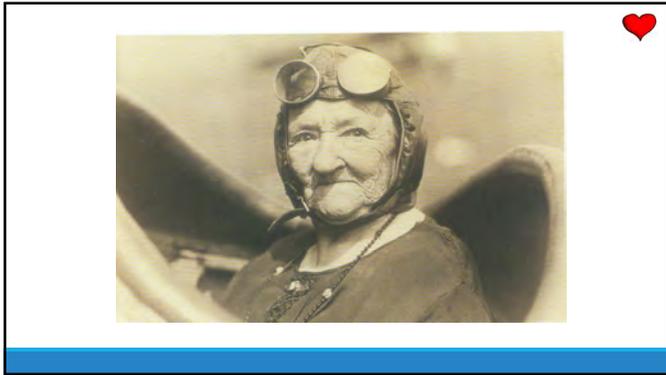
"It can't get away from
me... if I am in this place".













Christine Bryden

If I really try and think what time means to me now, it's like flickering images. It's something I might see in the calendar that I did a few weeks ago and then there's something I might do in a week or so, or things I've done today or might do later.

It's just like flickering images. It's not really a flow of time. Nor can I make sense of it.

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So if people say, "What did you do yesterday?" I have to look at the diary, I see what I did yesterday and it's what's in the diary, **it doesn't feel as if it really happened.** I don't really connect with it because there isn't a thread linking me back to it.

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Most days I feel like I'm **clinging to the precipice with my fingernails**. I know there's that looming black hole somewhere down there which is, you know, decline and despair, I don't want to go there. So I'm clinging on with every bit of **effort I've got to try and keep going, keep functioning, to keep speaking, keep rewiring.**

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In order to have this **façade of normality it takes a huge amount of effort**. So only really Paul probably knows what it's like, you know, afterwards when I just have to just rest because **it's just taken so much out of me to behave like a normal person.**

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I am determined to practice deep listening. I am determined to practice loving speech.
Thich Nhat Hanh

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More Than Words:
Scenario 1

❤️

Instructions:
You may only use facial expressions and body language. You may not use words or noises.

Message you want to send:
I have finished eating.
I want to go lie down for a nap.

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More Than Words:
Scenario 2

Instructions:

You must only use gibberish. You may NOT use understandable words. You may NOT use gestures or body language.

◦SAY: **Ebby bopo shoogy ma-kaa-daaa**

Message you want to send:

I need to go to the bathroom.

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Listen to not just the words but the:

- Body language
- Facial expressions
- Tone & Inflection of voice
- Emotional content

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When you hear the word
behavior what comes to mind?

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challenging
 Difficult
 BAD
Manage
Inappropriate



KICKING
 spitting
Yelling
 Eloping
HITTING
 hoarding
 uncooperative
 Wandering
 Aggressive



Behaviors
 =
Actions & Reactions

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Actions and Reactions ...

- Are a form of communication
- Can be an expression of a need
- Can be a response to our poor “behavior”

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Reasons Behind Actions and Reactions

Health Conditions	The task
Medications	Unmet Needs
Communication	Life Story/Personality
Environment	YOU

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Health

- | | |
|------------------|-----------------------|
| ✦ Medications | ✦ UTI |
| ✦ Constipation | ✦ Sick; a cold or flu |
| ✦ Dehydration | ✦ Pain |
| ✦ B12 deficiency | ✦ Chronic illness |
| ✦ Depression | ✦ Impaired senses |
| ✦ Fatigue | |
| ✦ Discomfort | |



Communication

- ✦ No eye contact
- ✦ Poor approach
- ✦ Talking to fast
- ✦ Not listening to them
- ✦ No patience
- ✦ Body language not matching your words



Task

- ✦ Not appropriate for their ability
- ✦ Too many steps
- ✦ It is unfamiliar
- ✦ Not communicated correctly



Environment

- ✦ Too large
- ✦ Too unfamiliar
- ✦ Poor sensory environment
- ✦ Too much stimulation; loud/busy
- ✦ Too unstructured

Unmet Needs



- ✦ Comfort
- ✦ Attachment
- ✦ Occupation
- ✦ Identity
- ✦ Love

Life Story



- ✦ What was the person's occupation/s?
- ✦ What did they like to do?
- ✦ What were their fears?
- ✦ Was there trauma in their life?
- ✦ What made them happy?

You





If we had a pill that made “behaviors” of people with dementia disappear, would this solve the “problem”?





Five Reasons to Move from Non-Pharmacological to PCC

1. Non-pharm medical lens
2. Need to see behaviors as form of communication
3. Overlooks other outcomes
4. Have value but do not transform the underlying environment/experience
5. Focus on disease rather than person



ramPaNt
normalcy



If you had no short-term memory and you struggle with concentration and word finding



A person came into your room,
opened your drapes and pulled your
blankets down and said,
"Sonya, It's time to get up."

If you have no short term memory
and have lost your social graces...



*Someone is in your home and they have long
beautiful hair so you walk up and say how pretty they
are and look like your sister and you stroke their hair.*

*Then someone you do not recognize comes up and
tells you that is inappropriate.*



What **is normal** to a
person with dementia?

Reacting to what seems to be
abnormal behavior
of others



“The shift from the old culture to the new is not
a matter of adding on a few items that
were missing, but of seeing almost every
feature in a different way.”

-Tom Kitwood, *Dementia Reconsidered*

take a deep breath

Be Present

SLOW DOWN
BE and PRESENT

WHEREVER YOU ARE.
BE ALL THERE.

Every person has needs.

Attachment

Comfort

LOVE

Identity

Occupation

Inclusion

From "Dementia reconsidered - the person comes first" by T. Kitwood, 1997, p. 82, Open University Press.



Research on Unmet Need

RCT- Compared two groups of residents with dementia

One group had individualized approaches specific to their identified unmet needs.

Other group just had educational presentation on agitation, behaviors, etc.

Intervention group had significant decreases in agitation, aggression, and increases in pleasure.

J. Cohen-Mansfield, M. Dakheel-Ali, M.S. Marx et al. Efficacy of nonpharmacological interventions for agitation in advanced dementia: A randomized, placebo-controlled trial. J Clin Psychiatry, 73 (2012), pp. 1255-1261

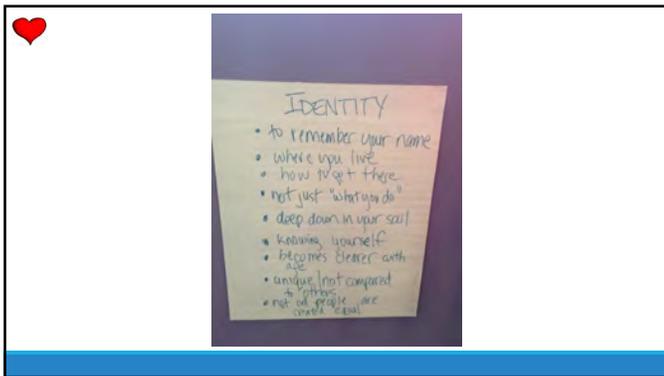
Identity



Identity



having a history
individuality
well-known
personhood





 I am struck by comments about what a person with dementia can and cannot do, realizing that there are many things a person can do, even with dementia. When you have dementia, **other people are always making this distinction for you**-what you can and cannot do- and you are often not given the chance to determine it for yourself.

 - Person with dementia



Identity

How many roles do you have?



The next time you communicate with someone who is not at his or her cognitive best, remind yourself of this:



"This interaction is not about me. This interaction is about someone who is seeking connection on terms that may not advance the interests or needs of my ego. I am going to go where your needs are taking you. I am going to be with you in that place, wherever and however it is. I am going to let my ego disappear now. I am going to love you in your image instead of trying to re-create you in mine."

Michael Verde, President, Memory Bridge

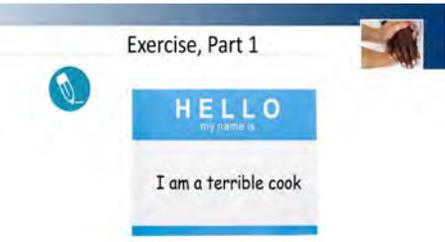


Identity

When I'm 64 84

Where will you live?
With anyone?
What do you like to do?
What are your hopes? dreams?

Exercise, Part 1



Module 6—Aging with a Person with Dementia: Making a Difference

What if that was written on a chart with other negative things about yourself?

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- Wanders constantly. Cannot sit still
- Has tendencies to take others belongings
- Is not patient – may get irritated or aggressive if made to wait too long
- Has intense muscle pain and can have spasms
- Has bursitis in knees
- Has arthritis in neck and upper back due to cervical kyphosis

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- Will only join in group activities once in a while. Tends to like to be the center of attention or be alone.
- Has abnormal fear of birds
- Had a speech impediments as a child.
- Roams into kitchen at all times of the day
- Has carpal tunnel syndrome and may not be able to use dominant hand

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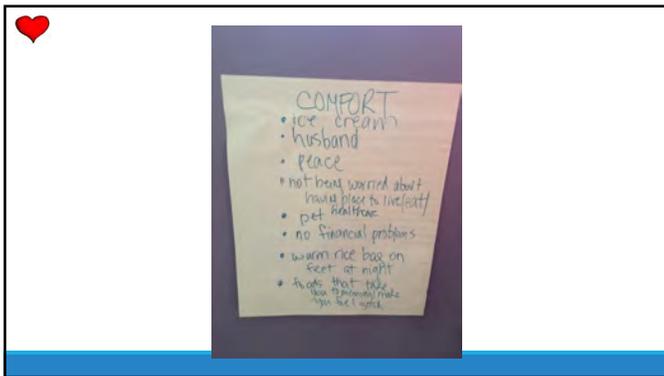
Comfort



Comfort



Soothing
 Security
 Warmth
 Safe
 Relaxed



Oh, the comfort — the inexpressible comfort of feeling safe with a person — having neither to weigh thoughts nor measure words, but pouring them all right out, just as they are, chaff and grain together; certain that a faithful hand will take and sift them, keep what is worth keeping, and then with the breath of kindness blow the rest away.

~

Dinah Craik, A Life for a Life, 1859





We say,
"This is your home."



Is it, really?

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What makes a home?

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Meaning of Home

Physical home
Social Home
Personal Home
-Judith Sixsmith (1986)
"Home is a central emotional and *sometimes* physical reference point in a person's life"

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Meaning of Home

Empowering

“Home is a place that highlights personal strengths and enables feeling of accomplishment, independence, responsibility, and usefulness.”

Molony S.(2010). The Meaning of Home: A Qualitative Metasynthesis. *Research in Gerontological Nursing*, 3(4) 291-307. doi: 10.3928/19404921-20100302-02

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Meaning of Home

Refuge

“...home as a place of comfort, safety, ownership, and insideness.”

“...fewer restrictions than the outside, public world.”

Molony S.(2010). The Meaning of Home: A Qualitative Metasynthesis. *Research in Gerontological Nursing*, 3(4) 291-307. doi: 10.3928/19404921-20100302-02

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Meaning of Home

Relationship

“togetherness”

“social insideness” from “a reservoir of accumulated social credit’ derived from *contributions* made to the community over time”

Molony S.(2010). The Meaning of Home: A Qualitative Metasynthesis. *Research in Gerontological Nursing*, 3(4) 291-307. doi: 10.3928/19404921-20100302-02

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Meaning of Home

Being known

“Home is a place where the self is recognized, significant, and known.”

Molony S.(2010). The Meaning of Home: A Qualitative Metasynthesis. *Research in Gerontological Nursing*, 3(4) 291-307. doi: 10.3928/19404921-20100302-02

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Meaning of Home

Self-Reconciliation

“...require significant efforts to redefine, reconcile, re-narrate, and reconfirm the meaning of “me” in the new environment.”

Molony S.(2010). The Meaning of Home: A Qualitative Metasynthesis. *Research in Gerontological Nursing*, 3(4) 291-307. doi: 10.3928/19404921-20100302-02

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Meaning of Home

Integration

“person-place integration as “feeling a part of life” and “being in meaningful relationship”

When person and place disengaged, **social withdrawal happens**

Molony S.(2010). The Meaning of Home: A Qualitative Metasynthesis. *Research in Gerontological Nursing*, 3(4) 291-307. doi: 10.3928/19404921-20100302-02

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What gives you that at home
ahhhhhhhh?



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"It's good to be home"

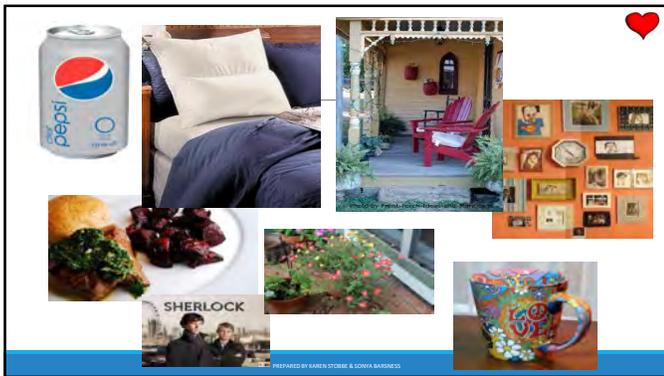


Each of you
take 3 Sticky Notes



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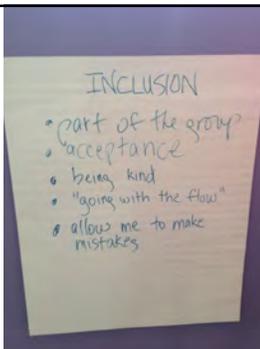




“Exclusion has an impact on the self. People with dementia experience feelings of embarrassment and stigma, their sense of self and self-esteem is negatively affected, and they experience loss of dignity, stress, and distress.”

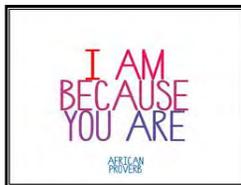
FROM “**DEMENTIA AND SOCIAL INCLUSION: MARGINALISED GROUPS AND MARGINALISED AREAS OF DEMENTIA RESEARCH, CARE AND PRACTICE**” - [ANTHEA INNES](#), [CAROLE ARCHIBALD](#), [CHARLIE MURPHY](#)

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Ubuntu





“I define connection as the energy that exists between people **when they feel seen, heard, and valued**; when they can give and receive without judgment; and when they derive sustenance and strength from the relationship.”

Brene Brown



How do we include people with dementia?

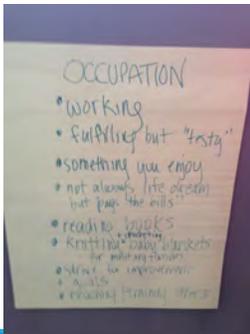
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Occupation



Purpose
Control
Doing what is important to you.





Becoming engaged, staying involved in a purpose, in purposeful activities is a key to living out our lives as happy, fulfilled individuals.



Richard Taylor

❤️

What give you purpose?

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❤️

If you had no one
expecting you



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❤️

Why leave your house?
Why leave your room?
Why get out of bed?

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❤️

"I need you."



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❤️

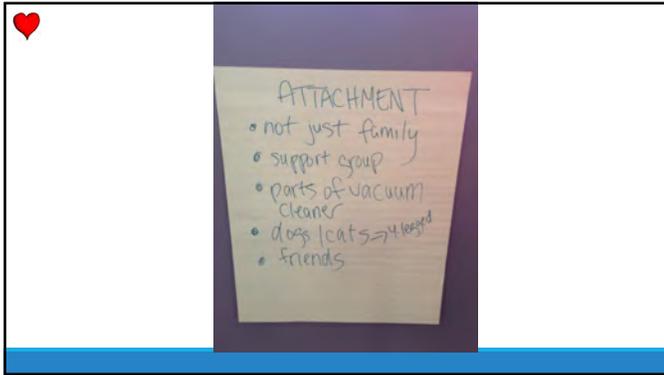
Are we giving people with dementia purpose or are we keeping people busy?

❤️

Attachment



- Connections
- Trust
- Nurture
- Relationship





When I am with someone with whom I have a relationship, I know that I am living. But, surrounded by people who are strangers, funneled into daily routines that are unfamiliar and uncomfortable, my life unknown to others, I'm not sure I am alive.



It's as though I have fallen out of life – perhaps into a living death... relationships are not only the heart of long-term care, they are the heart of life. And life ought to continue, wherever we live.

by Carter Catlett Williams, MSW,
Convener of The Pioneer Network

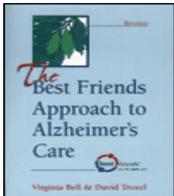


...Relationships are not only the heart of long-term care, they are the heart of life. And life ought to continue, wherever we live.

Google

Cortical signatures of cognition and their relationship to...
 Till Dementia Do Us Part: Alzheimer's Caregivers, Spouses...
 Changes in Relationships...
 Changing Roles and Relationships...
 Brain-Behavior Relationship – Alzheimer's Disease
 Trouble with our visual or spatial relationships...

Simply put the philosophy suggests that what a person with dementia needs most of all is a friend, a "Best Friend." This can be a family member, friend, or staff member who empathizes with their situation, remains loving and positive, and is dedicated to helping the person feel safe, secure and valued.



Virginia Bell, MSW
David Troxel, MPH



Why is relationship important?

Residents/clients and their family members consistently value the quality of their relationship with staff over other aspects of care. (Eaton 2000; Bowers, Fibich,& Jacobson 2001)

Staff say their relationship with residents/clients is what keep them committed to their jobs (Castle 2007, Bowers 2003)

From "Consistent Assignment: Cultivating Caring Relationships" by PHI



Theory of relational coordination

Relationships with the client are shaped by the relationships among all those who are caring for the client.

It is the community of relationships that shapes the client experience.

-Jody Hoffer Gittel, Brandeis University



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“The gerotranscendent individual, as we shall see, typically **experiences a redefinition of self and of relationships to others** and a new understanding of fundamental, existential questions. The individual becomes, for example, less self-occupied and at the same time more selective in the choice of social and other activities.

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There is an increased feeling of affinity with past generations and a decrease in interest in superfluous social interaction. The individual might also experience a decrease in interest in material things and a greater need for solitary 'meditation'. Positive becomes more important. There is also often a feeling of cosmic communion with the spirit of the universe, and a redefinition of time, space, life, and death.”

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What gives us purpose earlier in life



May or may not give us purpose later in life

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A few things we have
been thinking about

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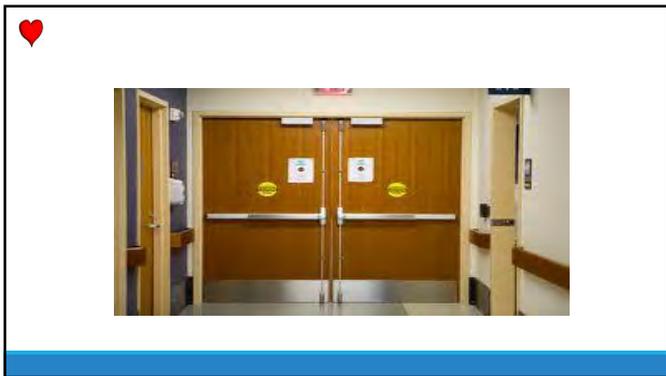


Buy In into Inclusion

We talk about getting 'buy in" from staff, from administrators, from board members, from anyone who is not in the room.

Buy in insinuates that you need a group of people to agree with what you are doing. Instead we need to all be included in the original ideas.





Is Behavior a Symptom of Dementia?

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LaQuisha

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What are three take
aways?

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*Thank you.
We appreciate your time
and the work you do.*

sonya@sbcgerontology.com
kstobbe1@gmail.com
